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Do Men's and Women's Accounts of Surviving a Stroke Conform to Frank's Narrative Genres?

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Abstract

We compared the illness narratives of 9 male and 9 female United Kingdom stroke survivors using Frank's typologies of illness narratives. Most respondents presented a single dominant narrative genre ("quest memoir," "restitution," "chaos," or a new "despair" genre); none presented quest manifesto or automythology narratives of social action or self-reinvention. We found no gender differences apparent in which genres respondents presented. Stroke severity and the degree of anticipated or actual recovery largely influenced which genre predominated in individual accounts. Contrary to some sociological understandings of gender and health, gender appeared to be less influential on stroke survivors' illness accounts than aspects of the illness, such as its severity.

Keywords

gender; illness and disease, chronic; illness and disease, experiences; interviews, unstructured; qualitative analysis; research, qualitative; stroke

Living with the effects of a serious chronic illness, such as stroke, can disturb a person's everyday life (Corbin & Strauss, 1985), sense of self-identity (Ellis-Hill, Payne, & Ward, 2000), and quality of life (Clarke & Black, 2005), and can disrupt their biography or life story (Bury, 2001). Stroke is a sudden, nonprogressive illness in which an interruption in the blood supply to the brain compromises its function, resulting in temporary or permanent impairments (Stroke Association, 2012d). It is the biggest cause of permanent disability worldwide. Its effects, which can include paralysis, aphasia,¹ epilepsy, limb weakness, fatigue, pain, visual disturbance, memory problems, and personality changes, can be life altering (Salter, Helings, Foley, & Teasell, 2008).

Faced with chronic illness, narrative is "one of several cultural forms available . . . for conveying, expressing or formulating our experience of illness and suffering" (Hydén, 1997, p. 64). Telling stories is a way that people make sense of illness (Charmaz, 1999), create and express meaning (Riessman, 1993), produce (Ricoeur, 1988) and maintain a sense of identity (Bury, 2001), and reconstruct a sense of order (Williams, 1984) in lives disrupted by illness. Given stroke's sudden onset and frequently severe impairments, stroke survivors might face particular challenges in making sense of their illness and reconstructing their biography, which are likely to be reflected in their illness narratives.

Identifying narrative "genres," described as the "most general storyline that can be recognized underlying the plot" (Frank, 1995, p. 75), can help show how narrators are attempting to make sense of and find meaning in their lives, identify which common cultural frameworks they use to structure events and experiences, and indicate how they want their story to be interpreted (Elliott, 2005). Based on his own experience of illness (a heart attack and testicular cancer) and on nonfiction illness stories, Arthur Frank suggested that three types of illness narrative—restitution, chaos, and quest—are available to people, at least in Western cultures.

Frank (1995) described these genres as devices that "aid listening to the ill" by helping the listener to untangle different, sometimes contradictory "narrative threads" (p. 76). Each genre reflects cultural and personal preferences; social institutions and interactions with listeners guide people toward particular narratives. Thus, his approach allowed us to examine individual, social, and

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Table 1. Defining Characteristics of Frank's Narrative Genres.

| Frank's Genre | Defining Characteristics |
|---|---|
| Restitution | Illness is transitory, not a threat to mortality, a temporary interruption, able to construct oneself as good as "new" or recovered, I am or will be fine, expect cure or remedy |
| Chaos | Despair, depression, futility, hopelessness, vulnerability, impotence, powerlessness, lack of control, no one in control, uselessness, no recognition for pain and suffering, emotional battering, lack of temporal order (unless told retrospectively) |
| Quest: Shared characteristics of memoir, manifesto, and automythology | Seek alternative ways of being ill; accept illness; emphasize gains from illness experience; illness as an opportunity, opening, or challenge; sense of purpose |
| Quest memoir: Unique characteristics | Simply accept illness, incorporate illness into life, trials told stoically, no special insight gained from illness experience |
| Quest manifesto: Unique characteristics | Demands for social reform or social action, special insight gained from illness experience |
| Quest automythology: Unique characteristics | Change of character, rebirth, self-reinvention |

cultural influences on personal narratives. It could also help health professionals, relatives, and researchers to better understand the experience of people who have had a major illness.

Frank (1995) saw a restitution narrative as the "culturally preferred narrative" (p. 83) promoted by modern medicine and reflected in popular culture (Lupton, 2003). A restitution story line can be summarized as, "Yesterday I was healthy, today I'm sick, but tomorrow I'll be healthy again" (Frank, p. 77). The narrative focuses on illness with a cure that will restore the person's previous state of health. Frank noted that restitution stories "no longer work" (p. 94) when illness is terminal or chronic. A return to health can be found in other narrative types; however, in such circumstances, the person's life is fundamentally altered, despite recovery.

Frank (1995) regarded the chaos narrative as the opposite of restitution: "Its plot imagines life never getting better" (p. 97). Chaos narratives "are told after your world has been 'unmade'" (p. 103); they can be characterized as "antinarratives" because "those who are truly *living* chaos cannot tell it in words" (p. 98) and the narrative has no temporal order. Frank suggested that chaos narratives are difficult to hear because they provoke anxiety.

In quest narratives the narrators "meet suffering head on; they accept illness and seek to *use* it" (Frank, 1995, p. 115), and search for "alternative ways of being ill" (p. 117). The goal of the quest might be unclear, but the quest is defined by the "belief that something is to be gained" (p. 115) from the illness experience. Frank maintained that most published autobiographical illness stories follow a quest narrative because, as the active agent in their own recovery, the ill person has a story to tell.

He identified three quest subtypes: "quest memoir," "quest manifesto," and "quest automythology." In a quest

memoir narrative the illness has simply been incorporated into the person's life: "Trials are . . . told stoically, without flourish" (Frank, 1995, p. 120). In quest manifesto narratives, there is a call for social reform. The narrator wants to use the insight gained from his or her suffering to improve his or her own and others' lives. Quest automythology narratives are characterized by self-reinvention, individual transformation, and metaphorical rebirth following traumatic illness. The defining characteristics of each genre are summarized in Table 1.

Frank did not develop his approach to illness narratives in relation to chronic or disabling conditions; however, other researchers have applied it to people's experiences of such conditions and to breast cancer. People with neurological symptoms (Nettleton, O'Malley, Watt, & Duffey, 2004), chronic obstructive pulmonary disease (Pinnock et al., 2011), or back pain (Vroman, Warner, & Chamberlain, 2009) predominantly presented chaos narratives. People with HIV or AIDs (Ezzy, 2000), spinal cord injury (Smith & Sparkes, 2004; Smith & Sparkes, 2005), or breast cancer (Thomas-MacLean, 2004) mostly presented restitution narratives. People with clinically diagnosed chronic fatigue syndrome tended to present quest memoir narratives (Whitehead, 2006). Stroke survivors' narrative genres might differ from those associated with some of these other illnesses because of their different effects, symptoms, prognoses, levels of diagnostic certainty, and/or the kind of people they typically affect.

None of the researchers using Frank's narrative approach explicitly compared women's and men's accounts. However, women and men might have different narrative genres available to them because their experiences of chronic illness might differ (Charmaz, 1995; Emslie et al., 2009; Emslie, Ridge, Ziebland, &

Hunt, 2007). Charmaz (1994) stated that men “more often view illness as an enemy to overcome or as an intrusive presence to control than do women” (p. 287); they tend to construct their illnesses as acute rather than chronic: thus cure is possible. Hence, men who have a chronic illness might favor certain genres, such as restitution, in their narratives, despite the improbability of a cure.

Based on research on men, researchers have suggested that chronic illness might undermine men’s identities by threatening their sense of masculinity (O’Brien, Hart, & Hunt, 2007), reducing their status in relation to other men, and reducing their power in relationships with women (Charmaz, 1995). Comparing the accounts of men with depression, coronary heart disease, and prostate cancer, O’Brien et al. suggested that “the losses men experience through illness can reveal what men think masculinity is and expose the practices of masculinity that participants engaged in prior to their illness” (p. 194). Although there has been considerable recent interest in the relationship between health and health behaviors and the way in which men “do” gender (West & Zimmerman, 1987; see, for example, Hunt, McCann, Gray, Mutrie, & Wyke, 2013, de Visser & McDonnell, 2013), researchers have rarely compared men’s and women’s experiences of chronic illness in empirical work (Emslie et al., 2007).

Our aim in this article is to provide an insight into men’s and women’s experiences of life after having a stroke through examining the particular genres they adopted in their narratives. We set out to answer three questions: Which, if any, of Frank’s (1995) narrative genres fit these stroke narratives? Are there similarities or differences in the narrative forms presented by men and women? How do other factors (e.g., stroke severity and degree of recovery) shape the kinds of narratives presented?

Methods

We conducted the narrative interview study from which we subsampled accounts for this analysis in the United Kingdom from 2006 to 2007. The Multicenter Research Ethics Committee approved the research methods, including secondary analysis of the data. Using diverse purposive sampling, we recruited 53 people affected by stroke who took part in 48 interviews via support groups, charities’ newsletters and Web sites, general practitioners, physiotherapists, occupational and speech therapists, nurses, press advertisements, and word of mouth. This included 25 male and 21 female stroke survivors, 6 of their relatives, and 1 family caregiver.

We sought variation in characteristics that might affect the experience of stroke and stroke care, including age of

onset, gender, ethnicity, socioeconomic status, and geographic location. Our inclusion criteria were adults who had suffered a minor or major stroke in the previous 10 years, including people with severe language and cognitive impairments. Those interested in participating received an information pack describing a study about personal experiences of stroke; they contacted the researcher directly or permitted their health professional to give the researcher their contact details. With this sampling approach it is impossible to know how many people saw study information but did not volunteer to participate.

Clare Dow conducted most interviews in respondents’ homes or another location of their choice. She is not a health professional, and therefore had no professional bias. She maintained a neutral but encouraging stance during the interviews. If an individual became emotional, she gave him or her the option of stopping the interview permanently or temporarily. Interviews lasted 1 to 5 hours and the interviewer adopted a narrative approach that allowed respondents to tell their own stories with minimal interruptions. Respondents gave written consent to participate in the interview, for us to audio and/or video record and transcribe it, and for secondary analysis of their data. Respondents checked, approved, and could edit their transcript.

Dow and Sally Wyke formulated interview prompts and questions in collaboration with a multidisciplinary project advisory group. The initial prompt was “Tell me the story of your stroke from when it first happened.” Subsequently, Dow asked semistructured questions to explore particular issues if the respondent had not already raised them. These included: “What do you think caused your stroke?” “What helped you to get back to doing things for yourself?” “What are your feelings about the future?” “Tell me about any good or bad experiences you have had with health professionals.” “Do you have any messages for health professionals?” “What would you like to tell families of people who have had a stroke?”

Because narrative analysis is time and resource intensive, Emma France subsequently conducted secondary analysis on a subsample of transcripts from 9 women and 9 men. We selected the subsample by matching women and men according to stroke severity and recency, type of impairment, their age, marital status, and whether they had children (see Table 2). We also tried to represent a range of sociodemographic characteristics.

We identified defining characteristics of Frank’s (1995) narrative genres, as summarized in Table 1, through a detailed reading of *The Wounded Storyteller*; we used these to identify dominant and other genres in each interview transcript. We considered each transcript in its entirety as a narrative. We used NVivo (QSR

Table 2. Respondents' Biographical and Illness Details.

| Sex | Women (N = 9) | Men (N = 9) |
|-----------------------------------|--|--|
| Marital status | 4 married, 2 widowed, 2 divorced, 1 single | 5 married, 2 widowed, 1 divorced, 1 single |
| Parental status | 7 with adult children, 1 with dependent children, 1 with no children | 7 with adult children, 1 with dependent children, 1 with no children |
| Ethnic origin or nationality | 5 White English, 2 White Scottish, 1 White German, 1 Pakistani | 3 White English, 2 White Scottish, 2 White Welsh, 1 Indian, 1 Black African |
| Stopped working because of stroke | 3 | 3 |
| Age at interview (mean) | 44-79 (62) | 47-85 (67) |
| Years since stroke (mean) | 0-6 (3) | 0-7 (3) |
| Type of stroke | Right hemisphere ischemic (n = 4), ischemic (n = 1), dissection of right carotid artery (n = 1), dissection of left carotid artery (n = 1), subarachnoid hemorrhage (n = 1), multiple TIAs ^a (n = 1) | Right hemisphere ischemic (n = 4), left hemisphere ischemic (n = 1), left hemisphere hemorrhage (n = 1), hemorrhage (n = 1), clot that prevented blood flow to left side of brain (n = 1), dissection of right carotid artery (n = 1), multiple TIAs (n = 1) (1 person had two types of stroke) |
| Effects of stroke ^b | No residual impairments (n = 2); could walk with walking stick (n = 2); severe walking difficulties, used mobility scooter (n = 1); central poststroke pain ^c (n = 2); pain (n = 3); arm weakness (n = 3); on antidepressants (n = 2); aphasia (n = 2); memory problems (n = 2); epilepsy (n = 1); auditory and visual hallucinations (n = 1); loss of peripheral vision (n = 1); partial paralysis (n = 1); left- or right-side weakness (n = 4) | No residual impairments (n = 1); walking difficulties or could walk with walking stick (n = 4); unable to walk, used wheelchair (n = 1); pain (n = 1); aphasia (n = 1); speech problems (n = 2); on antidepressants (n = 3); muscle spasms (n = 2); fatigue (n = 2); partial paralysis (n = 2); left- or right-side weakness (n = 4) |

^aTIA = Transient ischemic attack.

^bSome respondents had more than one of the listed impairments.

^cA form of neuropathic pain on which usual painkillers have little effect (Stroke Association, 2012b).

International, 2008) to facilitate management of the data. France coded all relevant excerpts in each transcript to “nodes” corresponding to Frank’s restitution, chaos, quest memoir, manifesto, and automythology genres. She exported excerpts into a matrix with each row representing one individual and each column representing a narrative genre. For each genre, we differentiated between narrative excerpts that referred to past experiences and emotions and those that referred to present ones.

The matrix enabled us to rigorously examine what and how much each individual said in relation to each genre. We identified an overarching current genre for an individual if his or her talk about the present day was dominated by a single genre. We could also identify whether other genres were present in the account. We compared which genres women and men presented and what they said. Dow, Kate Hunt, and Wyke independently coded 50% of the transcripts and compared their coding to France’s. We resolved discrepancies through discussion.

Findings

Applying Frank’s Approach to Stroke Narratives

Most respondents (i.e., 7 men, 8 women) presented a single dominant or overarching genre when recounting their current experiences. However, only one account (Nasreen)² did not contain multiple genres to characterize current experiences. Men and women presented similar dominant genres and similar patterns of multiple genres within their accounts (see Table 3). Although chaos was uncommon as an overarching genre, it was often present in respondents’ discussions of past and current experiences. In the following we focus on analysis of the current dominant genres. We describe accounts that were characterized by a quest memoir, restitution, or chaos narrative before describing the three respondents whose accounts had no overarching genre.

Table 3. The Occurrence of Each of Frank's (1995) Narrative Genres Within Interviews.

| Frank's Genre | | Restitution | | Chaos | | Quest Memoir | | Quest Manifesto | | Quest Automythology | |
|--------------------------|-------------------|---------------------------|------|---------|------|--------------|------|-----------------|------|---------------------|------|
| Dominant Genre | Name ^a | In Talk About the Present | Past | Present | Past | Present | Past | Present | Past | Present | Past |
| Quest memoir | Karen | X | X | | | X | X | X | | | |
| | Suzy | | | X | X | X | | X | | | |
| | Janet | X | X | X | | X | | | | | |
| | Helen | | X | | | X | X | | | | |
| | James | X | X | | | X | X | X | X | | |
| | Gerry | | | | X | X | | X | | | |
| | Sandeep | X | X | | | X | | | | | |
| | John | X | | X | X | X | X | X | | | |
| Chaos | Jenny | | X | X | | | | X | | | |
| | Nasreen | | | X | X | | | | | | |
| | Andrew | X | | X | X | X | | X | | | |
| Restitution | Anne | X | | | X | | | | | | |
| | Audrey | X | | | | X | X | | | | |
| | Lenny | X | | X | X | X | | X | | | |
| | George | X | | X | | X | | | | | |
| No single dominant genre | Marie | X | X | X | X | X | X | | | X | |

^aWe could not categorize two men's (Francis, Jack) accounts to Frank's narrative genres.

Quest Memoir

Four women and 4 men aged 54 to 85 years, who had had a stroke a few months to 6 years previously, presented accounts with a dominant quest memoir narrative. These people had chronic impairments from their stroke and most had significant functional deficits, such as severe aphasia or partial paralysis. Men's and women's quest memoir narratives were very similar in content. The main characteristic of these narratives was a relatively upbeat presentation of adaptation to stroke-related changes to their life, as illustrated here:

This thing has happened to me. . . . I just want to get on with my life and . . . I can't turn the clock back. I've got what I've got, go and deal with it and run my life accordingly. (James)

Adaptation took various forms within the interviews, including an apparent acceptance of impairments, looking for new occupations or interests when old ones could no longer be sustained, and/or finding new ways of doing tasks. For instance, Sandeep still led an active life, traveling long distances abroad and doing voluntary work, but he had started to reduce his commitments: "So I try to see that I still contribute. I do not go to so many meetings. I only go to the meetings where I could contribute something. I don't go just because my attendance has been ticked."

Three respondents in their 70s and 80s mentioned their age in explaining their response to their disabilities. They reasoned either that illness and disability are expected with greater age or that their losses were less problematic since they had retired and did not need to earn a living or raise children:

[The nurse] said, "Oh you've got to realize," she said, "your age and you see, you were very fortunate up to now. You've never had any serious illness up to now and plenty of people had." "Well," I said, "that's true enough," I said, "I can't grumble." I didn't have, and at my age I've been very fortunate. It's the only way to look at it. (Helen)

Some men and women also presented their experiences in a stoical way to avoid being seen to complain about their situation. For example, Janet, whose father had also had a stroke, said, "He's had a lot of problems, my dad, you know. So, but he just grins and gets on with it [laughs], and that's what I'm trying to do." In addition, most were grateful to have recovered significantly since their stroke, which appeared to aid their acceptance of any remaining limitations:

There's things I can't do, I'll never be able to do again, I know that. But I look upon it, I was lying in my bed after my stroke, the list of things that I could not do was a great big

list and the list of things I could still do was very, very small. So over the last year, I've transferred things over from "can't do" to "can do," and the lists are beginning to settle up. (James)

Commonly, these narratives contained reference to feeling lucky compared to others who had been more seriously affected by stroke. Two exceptions were Gerry and Karen, who had not experienced significant recovery; Karen felt her ongoing impairments were fairly minor, whereas Gerry still had severe aphasia.

Some people seemed to have come to terms with the consequences of the stroke partly because of what health professionals had told them, for example, about what level of recovery to expect, as Janet explained:

I love my driving and I drive twenty-six miles to my work, and he [the doctor] says, "You'll, you'll not drive." He says, "I don't think you'll be able to go back to your own work," he says. . . . It's the best way to get it, I suppose. If you're going to get any kind of news you're better getting straight, aren't you?

Still being able to participate in previously enjoyed activities, even if done differently, and to feel valued, were both important to people's positive attitudes. Sandeep, for example, had been given an award for his voluntary work and Karen felt influential in her new job: "I think I've made a positive contribution to the company as a whole." Often regret for what they had lost was apparent, but the overall tone was positive and accepting. Religious beliefs had also helped some people to come to terms with the stroke's impact. Overall, maintaining or finding purpose in life was an important part of (apparent) acceptance and adaptation to the effects of stroke for these 8 respondents.

Restitution

Only four accounts (2 women and 2 men aged 66 to 84 who had had a stroke 1 to 7 years previously) fitted a dominant restitution narrative. These accounts displayed a belief that the respondent was fully recovered or would fully recover: "I was very, very pleased about it all, especially now, a year later, when I feel perfectly all right. Perfectly normal person" (George). Anne and George had had "mini strokes" or transient ischemic attacks (TIAs),³ which had been surgically treated; Audrey had had a major stroke. George and Audrey believed they had recovered abilities initially affected by the stroke, such as vision and speech. Anne had been told to anticipate a full recovery. These three did not view their stroke as a chronic illness.

Lenny had more serious impairments, saying he initially "couldn't walk or do anything." He still had weakness on the left side of his body, walked slowly using a

walking stick for longer distances, and lived with his brother for practical support. Nonetheless, his account displayed the characteristics of a restitution narrative: "I had a belief that I am cured. . . . I'm better now. I could say one hundred percent better now." His considerable recovery, his limited day-to-day activities, and the fact that he had lived with the impacts of stroke for 7 years could explain why he felt recovered despite continuing limitations. Alternatively, he might have wanted to present himself as a recovered and capable "very strong person" in line with the culturally preferred restitution narrative. His reference to his strength hinted at the possible influence of his masculine identity in his use of the restitution genre.

Chaos

Three respondents (2 women and 1 man aged 47 to 76 who had had a stroke 2 to 5 years previously) presented accounts that predominantly conformed to chaos narratives. However, two of the narratives (Jenny, Andrew) were coherent rather than chaotic in form. Therefore, the lack of hope and depression they expressed might fit better with a new "despair" genre. Nasreen's account was somewhat chaotic in structure, although this could be partly because a freelance interviewer who spoke Punjabi carried out the interview.

All three respondents experienced severe permanent impairments affecting their mobility and ability to walk that limited their abilities to carry out social and day-to-day activities independently. Andrew and Jenny also described some cognitive impairment. They all had extreme difficulties adjusting to their losses, as illustrated by Jenny's description of the impact on her and her husband's life:

Both of us have found the effect of the stroke absolutely devastating because we were, you know, we were starting to do things. Like we'd started going on walking and dancing holidays and we were starting to do things like that that we found really, really enjoyable, and I suddenly can't do them anymore.

A common theme in these chaos or despair narratives was feeling out of control of daily life and dependent on family members to perform even basic tasks. Andrew felt he had lost his role as a man and a husband within the family, and was worried his wife might leave:

Well, it certainly changes things in terms of your role within the family because certainly now I'm dependent now [rather] than a partner. That's certainly how I feel, because the things we've taken responsibility, the things that need being done in the house, just paying bills, organizing things, just running a home, all those sorts of things, all the responsibility of doing that falls on my wife, which I don't like and I feel,

"What sort of a husband am I?" It does worry. I do sometimes think to myself, "What's my wife getting out of this relationship and how long are we going to be able to sustain it?"

Similarly Jenny's husband had to take on household tasks that she had previously performed, such as grocery shopping and cooking, which had caused conflict between them. Thus Jenny's and Andrew's accounts seemed to provide some evidence that stroke had disrupted the more traditional gender roles in their married lives.

Nasreen emphasized the impotence she felt. This was compounded by her inability to speak English, which prevented her from communicating with and receiving information from health professionals and social workers:

Nasreen (N): I can't straighten my fingers; my hand won't straighten.

Interviewer (I): Can't you ask them [health professionals] to help?

N: How can I ask them?

I: Can't your sons ask them?

N: Sons can help, but they won't take me to hospital.

(Interview translated from Punjabi)

All three respondents were taking antidepressants, and Jenny and Andrew explicitly referred to being depressed: "I do often feel very suicidal because I'm finding it impossible to think of things I can look forward to except a game of Scrabble and that's not always available" (Jenny). They also described significant emotional suffering, including as a result of their health care experiences. Andrew, for example, related his traumatic and disempowering experiences in hospital after the stroke: "I did feel very, very alone. It would have been nice to have thought I had a friend in the hospital somewhere, other than my visitors that were coming in to see me."

Nasreen had been told her recovery would be slow, whereas Jenny's and Andrew's health professionals had left them with no hope of recovery. None had experienced much, if any, improvement since their stroke. The severity of their disability and the unlikelihood of improvement could explain why these three accounts largely conformed to chaos narratives.

Interviews That Lacked a Dominant Narrative Genre

No one presented an account consistent with a dominant quest manifesto or quest automythology genre. Some women's and men's interviews contained elements of quest manifesto, but only Marie's account contained elements of quest automythology. Marie was in her 40s and had suffered from central poststroke pain⁴ since her stroke 3 years before. Her account was almost equally

dominated by the often contradictory use of restitution, quest memoir, and chaos genres, but she did not use quest manifesto.

She repeatedly presented herself as a capable, committed single mother who was striving to cope simultaneously with her impairment and motherhood. Overall, Marie appeared to be trying to present a quest memoir narrative while really wanting a cure (restitution narrative). She corrected herself on a couple of occasions to give a more positive, optimistic presentation: "I'm sorry. I'm not supposed to get upset, am I? I'm supposed to be being positive and helpful." She then slipped back into a description of daily life more in keeping with a chaos genre: "My social life's completely changed. My work life has changed. In effect, it, it's blown my whole world apart." This strongly suggested that Marie was aware that chaos is not a preferred public narrative type.

At numerous points throughout the interview she expressed hope for a miracle cure for her pain, in line with a restitution genre. She also used powerful imagery to describe her personal transformative process, thus conforming at times to a quest automythology genre:

I feel as if it's my second chance now. It's as if I had one life and it ended when I had the stroke, and I now have a completely new life. . . . I feel like I've been through a baptism of fire and come out at the other end . . . crawled out of the other end in effect, and I've had to claw my way back to health as I knew it before.

In the remaining two interviews (Francis and Jack) we could code very little talk to any of the genres. Both lacked narrative form. Both men were at an early stage in recovery, having had strokes within the previous year. The uncertainties about their future might have made it difficult for them to judge the stroke's long-term impact on their life. However, we were able to use Frank's framework to characterize the narratives of other respondents who faced uncertain future recovery following a recent stroke. Another possibility is that the men were unable to tell a story because of communication problems (McKevitt, Redfern, Mold, & Wolfe, 2004)—for example, Jack had impaired speech—or because they were denying the reality of their illness by "neither acknowledging suffering nor allowing a story of it to take form" (Charmaz, 1999, p. 373).

Discussion

We explored men's and women's experiences of life after having a stroke using a gender-comparative lens in which we explicitly asked whether men or women were more likely to adopt particular narrative genres or "story lines" in their illness accounts. We set out to answer three questions:

Which, if any, of Arthur Frank's (1995) narrative genres fit these stroke narratives? Are there similarities or differences in the narrative forms presented by men and women? How do other factors (e.g., stroke severity and degree of recovery) shape the kinds of narratives presented?

We found Frank's (1995) conceptualization of narrative genres relevant to accounts of life after a stroke (a chronic illness), even though he developed it largely with reference to potentially curable illnesses (e.g., cancer). We identified an overarching narrative genre in most accounts. The most common genre was quest memoir, a minority presented a restitution or chaos narrative, no one presented a quest manifesto or quest automythology narrative. Thus, only certain narrative forms appeared to be available to these stroke survivors. Some of the chaos narratives were not chaotic in structure; therefore they appear better suited to a new despair genre.

The same genres seemed to be available to and presented by both women and men in their accounts. We were aware that men might see the effects of stroke as acute, hence curable (Charmaz, 1994), and therefore favor a restitution narrative, but this did not seem to be the case. In future studies, researchers could use Frank's (1995) approach to explore whether women and men who have other chronic illnesses present similar or different narrative forms. There might be subtle impacts of gender on these accounts that were not apparent in our analysis of the overall genre. Articles about aspects of depression (Emslie et al., 2007), cancer (Emslie et al., 2009; Hilton, Emslie, Hunt, Chapple, & Ziebland, 2009), and having multiple chronic conditions (Hurd Clarke & Bennett, 2013), in which researchers used thematic analysis, revealed both similarities and differences in women's and men's reported experiences.

We recognize that our approach, organized around our focus on Frank's (1995) typologies, is just one way of explicitly examining gender's role in the impact of illness on identity. Our approach might seem to deemphasize differences "within" women and "within" men and to valorize differences based on biological sex. However, we contend that only by taking this approach could we convincingly argue that women and men stroke survivors used the narrative types in similar ways. Other analyses could focus on gender through, for example, a more detailed examination of how men and women use language to describe the reconstruction or fracturing of identity. This could reveal the many ways in which the "doing" of health is entwined with the social construction of gender.

A combination of the severity of stroke (and impairment), the degree of actual or expected recovery, and for some respondents, the recency of their stroke appeared to be important influences on which overarching genre they

presented in their accounts. The combined effect of these factors probably would not have been apparent in a more homogeneous group of stroke survivors, thus highlighting a benefit of our sampling approach. Most of the respondents who presented a quest memoir narrative felt fortunate to have recovered significantly, despite still having moderate to severe limitations. Those who presented a restitution narrative generally had strokes that had caused less disability. Respondents who presented a chaos or despair narrative were among the most physically disabled, had experienced little improvement since stroke, and had little hope of further recovery.

Dominant quest and chaos narratives might not be unexpected among stroke survivors who are either able (quest) or unable (chaos) to accept the permanent life changes that usually characterize stroke. In contrast, dominant restitution narratives should be unlikely if a person has significant functional deficits, because a cure is not possible when illness is chronic (Frank, 1995). If impairment is likely to be permanent, the restitution genre might be "unhealthy" because it can prevent the person from developing a different identity or sense of self (Smith & Sparkes, 2004, p. 625).

One of the respondents who presented a restitution narrative regarded himself as cured despite ongoing disability. This could be adaptive rather than unhealthy because it allowed him to maintain his former masculine identity but did not involve a (perhaps) unrealistic hope for a cure. Nonetheless, for some people a quest narrative might be emotionally healthier, indicating that at some level they have accepted impairment and "moved on."

The absence of overarching quest manifesto and automythology narratives could be because these genres involve the most fundamental shifts in identity and/or behavior. They entail self-reinvention as a result of illness (quest automythology) or acquisition of deep insight that prompts social action (quest manifesto); thus they might require the most effort to achieve. Similarly, Thomas-MacLean (2004) and Whitehead (2006) did not find these quest genres for women with breast cancer or people with chronic fatigue syndrome, respectively. These quest narratives might be relatively rare outside of the autobiographies on which Frank (1995) drew.

Perhaps people who publish their illness accounts of overcoming adversity have a particular story of self-development to tell (e.g., Sacks, 1984). However, Secrest and Thomas (1999) observed that some individuals experience stroke as a "catalyst" (p. 244) for profound life changes. Future research could explore under which circumstances stroke survivors and people with other chronic illnesses present stories of social reform or individual transformation.

We observed that what health professionals said about the illness and its likely prognosis soon after a patient had

had a stroke could also influence which genres were most (and least) accessible to people. For some people, their interactions with health professionals led them to anticipate complete recovery (restitution), some were helped to accept their impairment (thus making quest memoir narratives more readily available), whereas others were left with little hope (chaos or despair narratives). Thus, the wider cultural availability of genres based on societal expectations of acceptable illness narratives could play a role in which genres people present (Dutta, 2008; Frank, 1995).

Those with power in the dominant culture, such as health professionals or health care institutions, can determine which narrative types circulate within the culture (Dutta, 2008). Health professionals should be aware of their own preferences for a particular type of narrative (Soundy, Smith, Cressy, & Webb, 2010) and recognize their potential influence during interactions on a person's attitude to their illness and recovery, hence on their illness narratives.

Other important factors in some of the respondents' acceptance of stroke included not wanting to be seen to complain, religious belief, and accepting illness as part of advancing age. Other researchers have also identified older age as important in acceptance of stroke for working-class Londoners (Pound, Gompertz, & Ebrahim, 1998) and male U.S. veterans (Faircloth, Boylstein, Rittman, Young, & Gubrium, 2004), and found that religious faith facilitated acceptance in the latter group (Hinojosa, Boylstein, Rittman, Hinojosa, & Faircloth, 2008). We have extended these findings to a diverse United Kingdom-wide sample of stroke survivors.

Our findings and those of other researchers suggest that the nature of a person's illness is another important influence on which genres are available and presented within their illness narratives. For instance, several researchers found that people who had severe illness with little hope of cure presented chaos narratives (Nettleton et al., 2004; Pinnock et al., 2011; Vroman et al., 2009). Only one, who focused on people who had a clinical diagnosis of chronic fatigue syndrome (Whitehead, 2006), also found that the majority of respondents presented quest memoir narratives. Stroke and chronic fatigue syndrome seem to have little in common, although both involve clinically diagnosed chronic impairments.

Some of our findings reflect those of previous research on experiences of stroke. The chaos and despair narratives of severely disabled respondents in our study echoed Becker's (1993) descriptions of the permanent disruption to people's lives and identities following a severe stroke, when performing even simple, everyday tasks became impossible. Having purpose in life, gained through participating in valued activities, appeared to have helped many of the respondents in our study (who presented

quest memoir narratives) to accept the long-term effects of stroke. Other researchers have also reported that some stroke survivors were adaptable, especially those with mild to moderate deficits (Kirkevold, 2002), and that elderly stroke survivors strove for continuity in life by maintaining activities that were most important to their self-identity (Clarke & Black, 2005).

Strengths of this article are that we have explicitly described how we operationalized and applied Frank's genres to our data (so our approach can be replicated), and we used independent coding to verify our interpretations of many accounts. Some researchers have been less explicit in how they have applied Frank's theoretical framework. Furthermore, identifying all genres presented—the various threads of the story—enabled us to untangle contradictory elements in accounts and highlighted the importance of multiple genres in the narratives.

Although Frank (1995) suggested that different genres are told at different times during an illness, we observed that respondents drew on several genres concurrently; thus, the accounts were even more complex than we might have predicted. Some researchers using Frank's approach identified only the dominant narrative genre (Ezzy, 2000; Nettleton et al., 2004; Pinnock et al., 2011; Smith & Sparkes, 2004; Smith & Sparkes, 2005; Vroman et al., 2009). An awareness of the use of multiple genres could facilitate listening to illness narratives, thus recognition of the complexity of the illness experience (Frank; Thomas-MacLean, 2004). This could help health and social care professionals to hear some of the more difficult issues affecting stroke survivors, beyond a more upbeat genre that is more apparent in their accounts.

Prior to interview the respondents in our study had consented to the use of video, audio, or text-only extracts of their accounts on a public Web site on experiences of stroke.⁵ Hence, their accounts might differ from narratives told in other contexts, such as those told anonymously or those shared with a single other person. Furthermore, it is likely that respondents understood the cultural preference for quest (and restitution) as opposed to chaos narratives. Frank (1995) suggested that chaos narratives are difficult to hear and least socially acceptable. We acknowledge that every story (whether public or not) is something that is cocreated by both the narrator and the interviewer (Squire, 2008), and is a product of one moment in time; different stories might be told on a different day or in a different context. Neither we nor Frank have suggested that the overarching narrative genres that respondents use to frame their stories are necessarily fixed or enduring.

Contrary to some sociological understandings of gender and health (Charmaz, 1995; Connell, 2005), we and other researchers (Emslie et al., 2007, 2009; Hilton et al.,

2009; Hilton, Hunt, Emslie, Salinas, & Ziebland, 2007; Hurd Clarke & Bennett, 2013) have suggested that women's and men's experiences of certain serious illnesses are more alike than dissimilar. This highlights the value of comparing women's and men's experiences and challenges taken-for-granted tacit assumptions that they will react differently to ill health. From our analysis, it appears that gender might be less influential on a person's experiences of stroke (and perhaps of other chronic illnesses) than an idiosyncratic combination of factors, including the severity and nature of the illness, and the degree of anticipated or actual recovery.

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Notes

1. Aphasia affects the understanding and use of language and can affect understanding money and time (Stroke Association, 2012a).
2. All names are pseudonyms.
3. A transient ischemic attack is similar to a full stroke, but its symptoms last from a few minutes to 24 hours. It indicates risk of an imminent major stroke (Stroke Association, 2012c).
4. A form of neuropathic pain on which usual painkillers have little effect (Stroke Association, 2012b).
5. http://www.healthtalkonline.org/Nerves_and_brain/Stroke

References

- Becker, G. (1993). Continuity after a stroke: Implications of life-course disruption in old age. *Gerontologist*, 33, 148-158. doi:10.1093/geront/33.2.148
- Bury, M. (2001). Illness narratives: Fact or fiction? *Sociology of Health and Illness*, 23, 263-285. doi:10.1111/1467-9566.00252
- Charmaz, K. (1994). Identity dilemmas of chronically ill men. *Sociological Quarterly*, 35, 269-288. doi:10.1111/j.1533-8525.1994.tb00410.x
- Charmaz, K. (1995). The body, identity, and self: Adapting to impairment. *Sociological Quarterly: Official Journal of*

- the Midwest*, 4, 657-680. doi:10.1111/j.1533-8525.1995.tb00459.x
- Charmaz, K. (1999). Stories of suffering: Subjective tales and research narratives. *Qualitative Health Research*, 9, 362-382. doi:10.1177/104973239900900306
- Clarke, P., & Black, S. E. (2005). Quality of life following stroke: Negotiating disability, identity, and resources. *Journal of Applied Gerontology*, 24, 319-336. doi:10.1177/0733464805277976
- Connell, R. W. (2005). *Masculinities*. Cambridge, MA: Polity Press.
- Corbin, J., & Strauss, A. (1985). Managing chronic illness at home: Three lines of work. *Qualitative Sociology*, 8, 224-247. doi:10.1007/BF00989485
- de Visser, R. O., & McDonnell, E. J. (2013). "Man points": Masculine capital and young men's health. *Health Psychology*, 32, 5-14. doi:10.1037/a0029045
- Dutta, M. J. (2008). *Communicating health*. Cambridge, UK: Polity Press.
- Elliott, J. (2005). (Ed.). *Using narrative in social research—Qualitative and quantitative approaches*. Thousand Oaks, CA: Sage.
- Ellis-Hill, C. S., Payne, S., & Ward, C. (2000). Self-body split: Issues of identity in physical recovery following a stroke. *Disability and Rehabilitation*, 22, 725-733. doi:10.1080/09638280050191990
- Emslie, C., Browne, B., MacLeod, U., Rozmovits, L., Mitchell, E., & Ziebland, S. (2009). "Getting through" not "going under": A qualitative study of gender and spousal support after diagnosis with colorectal cancer. *Social Science and Medicine*, 68, 1169-1175. doi:10.1016/j.socscimed.2009.01.004
- Emslie, C., Ridge, D., Ziebland, S., & Hunt, K. (2007). Exploring men's and women's experiences of depression and engagement with health professionals: More similarities than differences? A qualitative interview study. *BMC Family Practice*, 8(43). doi:10.1186/1471-2296-8-43
- Ezzy, D. (2000). Illness narratives: Time, hope and HIV. *Social Science and Medicine*, 50, 605-617. doi:10.1016/S0277-9536(99)00306-8
- Faircloth, C. A., Boylstein, C., Rittman, M., Young, M. E., & Gubrium, J. (2004). Sudden illness and biographical flow in narratives of stroke recovery. *Sociology of Health and Illness*, 26, 242-261. doi:10.1111/j.1467-9566.2004.00388.x
- Frank, A. W. (1995). *The wounded storyteller—Body, illness and ethics*. Chicago: University of Chicago Press.
- Hilton, S., Emslie, C., Hunt, K., Chapple, A., & Ziebland, S. (2009). Disclosing a cancer diagnosis to friends and family: A gendered analysis of young men's and women's experiences. *Qualitative Health Research*, 19, 744-754. doi:10.1177/1049732309334737
- Hilton, S., Hunt, K., Emslie, C., Salinas, M., & Ziebland, S. (2007). Have men been overlooked? A comparison of young men and women's experiences of chemotherapy-induced alopecia. *Psycho-Oncology*, 17, 577-583. doi:10.1002/pon.1272
- Hinojosa, R., Boylstein, C., Rittman, M., Hinojosa, M. S., & Faircloth, C. A. (2008). Constructions of continuity after

- stroke. *Symbolic Interaction*, 31, 205-224. doi:10.1525/si.2008.31.2.205
- Hunt, K., McCann, C., Gray, C., Mutrie, N., & Wyke, S. (2013). "You've got to walk before you run." Positive evaluations of a walking programme as part of a gender sensitised weight management programme delivered to men through professional football clubs. *Health Psychology*, 32, 57-65. doi:10.1037/a0029537
- Hurd Clarke, L., & Bennett, E. (2013). "You learn to live with all the things that are wrong with you": Gender and the experience of multiple chronic conditions in later life. *Ageing and Society*, 33, 342-360. doi:10.1017/S0144686X11001243
- Hydén, L. (1997). Illness and narrative. *Sociology of Health and Illness*, 19, 48-69. doi:10.1111/j.1467-9566.1997.tb00015.x
- Kirkevoid, M. (2002). The unfolding illness trajectory of stroke. *Disability and Rehabilitation*, 24, 887-898. doi:10.1080/09638280210142239
- Lupton, D. (2003). *Medicine as culture* (2nd ed.). London: Sage.
- McKevitt, C., Redfern, J., Mold, F., & Wolfe, C. (2004). Qualitative studies of stroke: A systematic review. *Stroke*, 35, 1499-1505. doi:10.1161/01.STR.0000127532.64840.36
- Nettleton, S., O'Malley, L., Watt, I., & Duffey, P. (2004). Enigmatic illness: Narratives of patients who live with medically unexplained symptoms. *Social Theory and Health*, 2, 47-66. doi:10.1057/palgrave.sth.8700013
- O'Brien, R., Hart, G. J., & Hunt, K. (2007). "Standing out from the herd": Men renegotiating masculinity in relation to their experience of illness. *International Journal of Men's Health*, 6, 178-200. doi:10.3149/jmh.0603.178
- Pinnock, H., Kendall, M., Murray, S. A., Worth, A., Levack, P., Porter, M., . . . Sheikh, A. (2011). Living and dying with severe chronic obstructive pulmonary disease: Multi-perspective longitudinal qualitative study. *BMJ Supportive and Palliative Care*, 1, 174-183. doi:10.1136/bmjspcare.d142rep
- Pound, P., Gompertz, P., & Ebrahim, S. (1998). Illness in the context of older age: The case of stroke. *Sociology of Health and Illness*, 20, 489-506. doi:10.1111/1467-9566.00112
- QSR International Pty Ltd. (2008). NVivo qualitative data analysis software (Version 8.0) [Computer software]. Doncaster, Australia: Author.
- Ricoeur, P. (1988). *Time and narrative* (Vol. 3). Chicago: University of Chicago Press.
- Riessman, C. K. (1993). *Narrative analysis*. Thousand Oaks, CA: Sage.
- Sacks, O. W. (1984). *A leg to stand on*. London: Picador.
- Salter, K., Helings, C., Foley, N., & Teasell, R. (2008). The experience of living with stroke: A qualitative meta-synthesis. *Journal of Rehabilitation Medicine*, 40, 595-602. doi:10.2340/16501977-0238
- Secrest, J. A., & Thomas, S. P. (1999). Continuity and discontinuity: The quality of life following stroke. *Rehabilitation Nursing: The Official Journal of the Association of Rehabilitation Nurses*, 24, 240-246. doi:10.1002/j.2048-7940.1999.tb02190.x
- Smith, B., & Sparkes, A. (2004). Men, sport, and spinal cord injury: An analysis of metaphors and narrative types. *Disability and Society*, 19, 613-626. doi:10.1080/0968759042000252533
- Smith, B., & Sparkes, A. C. (2005). Men, sport, spinal cord injury, and narratives of hope. *Social Science and Medicine*, 61, 1095-1105. doi:10.1016/j.socscimed.2005.01.011
- Soundy, A., Smith, B., Cressy, F., & Webb, L. (2010). The experience of spinal cord injury: Using frank's narrative types to enhance physiotherapy undergraduates' understanding. *Physiotherapy*, 96, 52-58. doi:10.1016/j.physio.2009.06.001
- Squire, C. (2008). Experience-centred and culturally-oriented approaches to narrative. In M. Tamboukou (Ed.), *Doing narrative research* (pp. 41-63). London: Sage.
- Stroke Association. (2012a). *Communication problems after stroke*. Retrieved from www.stroke.org.uk/factsheet/communication-problems-after-stroke
- Stroke Association. (2012b). *Pain after stroke*. Retrieved from www.stroke.org.uk/factsheet/pain-after-stroke
- Stroke Association. (2012c). *What is a stroke?* Retrieved from www.stroke.org.uk/factsheet/what-is-a-stroke
- Stroke Association. (2012d). *Who is at risk?* Retrieved from www.stroke.org.uk/about/who-risk
- Thomas-MacLean, R. (2004). Understanding breast cancer stories via Frank's narrative types. *Social Science and Medicine*, 58, 1647-1657. doi:10.1016/S0277-9536(03)00372-1
- Vroman, K., Warner, R., & Chamberlain, K. (2009). Now let me tell you in my own words: Narratives of acute and chronic low back pain. *Disability and Rehabilitation*, 31, 976-987. doi:10.1080/09638280802378017
- West, C., & Zimmerman, D. H. (1987). Doing gender. *Gender and Society*, 1, 125-151. doi:10.1177/0891243287001002002
- Whitehead, L. C. (2006). Quest, chaos and restitution: Living with chronic fatigue syndrome/myalgic encephalomyelitis. *Social Science and Medicine*, 62, 2236-2245. doi:10.1016/j.socscimed.2005.09.008
- Williams, S. J. (1984). The genesis of chronic illness: Narrative re-construction. *Sociology of Health and Illness*, 6, 175-200. doi:10.1111/1467-9566.ep10778250

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